

Advocacy



Advocacy can mean many things for many different people and situations. For the purposes of this plan, advocacy refers to developing the public health infrastructure needed to implement the Montana Comprehensive Cancer Control (CCC) Plan. It also refers to advancing the legislative policy that can improve the ability to prevent and treat cancer, and improve survivors' quality of life from diagnosis through the course of the disease.

Montana's public health system is made up of a complex network of people, systems, and organizations in public and private sectors. By improving the infrastructure we are strengthening all parts of the public health system that work

to execute the Montana CCC Plan. Public policy can result in better healthcare, support for research, and the creation of an effective infrastructure. Collectively, these can lead to reductions in cancer incidence and mortality.

Besides being a medical, social, psychological, and economic issue, cancer is a political issue.

Lawmakers at all levels make decisions that impact our ability to reach our cancer control goals. For example, decision makers determine how much money goes into cancer research, the policies that affect the public health infrastructure, and state funding levels for public health.

Public health policy impacts thousands and is a critical tool for realizing the goals of this plan. Educating the public, the media, and decision makers about the importance of sound policy could ultimately reduce cancer incidence and mortality rates and improve cancer survivors' quality of life.

Advocacy is the pursuit of influencing outcomes — including public policy and resource allocation decisions within political, economic, and social systems and institutions — that directly affect lives.

— David Cohen, Co-Director, Advocacy Institute



John Bohlinger is the Lieutenant Governor of Montana and a cancer survivor. He is quick to say how important it is to be open about his experience, and believes that by talking about cancer, we can begin to effect change.

John got a physical exam every year, so he was well aware of it

when his PSA levels started creeping up. The prostate-specific antigen (PSA) is a protein produced by the cells of the prostate gland. The PSA test, which measures the levels of the antigen in the blood, went from one the first year, to two the next, then four, then eight. Year-by-year, it was doubling. He was 58 years old when he learned that he had prostate cancer.

He started educating himself. He researched the disease on the internet, and discussed it with his doctor, his wife, family, and friends. After a lot of thought, John decided that surgery was his best and safest option, particularly since he had a very strong family history of the disease. John's father was 49 when he died, and John lost his mother a few years afterward. Both died of cancer. It came down to the fact that he wanted to eliminate the presence of cancer altogether. The surgery went well, and John has been a survivor for more than six years.

"I believe it's important to tell our stories. My wife, Bette, offered a shining example of courage and grace in the face of adversity. It isn't just about surviving — it's how we live that defines us."

— Lt. Governor John Bohlinger

Update: Montana suffered a grievous loss when Bette Bohlinger succumbed to cancer in January 2006.

Bette Bohlinger was always moderate in her habits — she ate right, exercised every day, watched her weight, and she'd gotten a clean bill of health from a physical in October. Because her mother had been diagnosed with breast cancer when Bette was a little girl, she had always worked hard to avoid the risk factors that can lead to cancer. It seemed to pay off. She was healthy, active, and had lots of energy. She'd needed that energy for the past year while she and her husband, John, worked on a vigorous gubernatorial campaign for Brian Schweitzer. When Brian Schweitzer won the race for governor, she and John were jubilant. Life was good. They were ready to celebrate by meeting their family in Big Sky for a four-day Thanksgiving holiday. As soon as they arrived, though, Bette developed a severe headache she couldn't shake.

As soon as she got home to Billings, she went to see her doctor. The doctor asked if there'd been other symptoms. "Nothing except some bruising I can't explain," Bette paused, and then, remembering something she'd read, "Maybe you should test me for leukemia." She was half joking, and was surprised when her doctor took the suggestion seriously.

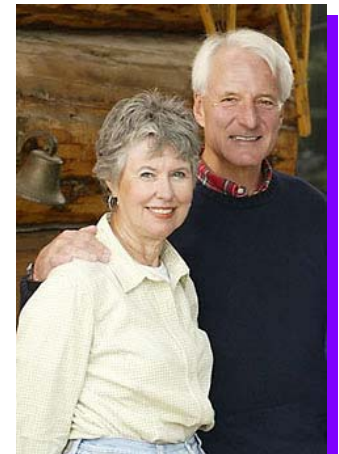
Bette was stunned when she learned that she had acute myeloid leukemia. Her platelet level was so low that her headache had actually been caused by bleeding on the surface of her brain. She started treatment the same day, and she was given a 10 - 20 percent chance of survival for one year.

"I was stunned when I learned that I had leukemia," Bette said. "I'd practically been the poster child for moderation. Suddenly I found myself thinking that it hadn't mattered after all. But I've since changed my mind. I've recovered much more quickly than anyone expected, and I know it's because I've lived such a healthy life."

It was touch and go for months. For several days running, she had a temperature of 106°. Her treatment team had no option but to put her on a sheet of ice water to try to bring down the fever. Her kidneys and liver started to fail, and her heart was racing at 140 beats per minute. Bette said she doesn't remember those days. John does. With tears in his eyes, he remembers the doctor coming by early one morning to say, "I'm not sure that she's going to live through this day. Call your kids and tell them to come say goodbye to their mother." All six of the Bohlinger's children came, from all points of the country.

Day by day, Bette survived. She attributed much of it to the wonderful care she received. Chemotherapy lasted from the end of November until the first of May. Her hair had grown back and food had begun to taste good again when she went in for her three-month check-up. They found no evidence of cancer, and her doctors said her chances of survival had grown to 60 - 70 percent for one year. She was thankful that they continued to grow with every passing day.

"One thing that really helped me was the big stack of cards and letters I received every day, many from people I didn't even know. It helped to know that people were praying for me and thinking of me, to know that people cared. If I could pass on two things I've learned from all this, I would encourage people to take care of themselves, and to be open about their cancer experiences. Share your story. Speak out. We can use our stories to give others hope." — Bette Bohlinger



Goal I: Implement Montana's Comprehensive Cancer Control Plan.

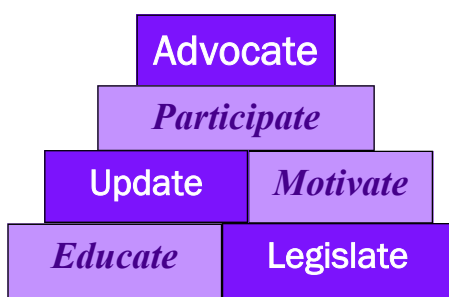
Objective I.1: *Increase political support for public health and implementation of the Montana CCC Plan.*

Baseline: During the 2005 Montana Legislative Session, two bills and one Senate Joint Resolution were introduced that had a direct connection to cancer, and none mentioned the Montana CCC Plan

Outcomes: Cancer will be raised as a campaign issue during the next several political cycles, and an increased number of resolutions and/or bills addressing cancer-related issues will be presented during the legislative sessions and in the U.S. Congress. By 2006, establish a baseline number of U.S. congressional bills with a direct connection to cancer

Data sources: Montana legislative website; American Cancer Society (ACS) Legislative Survey; the ACS National Government Relations Department

Strategy 1	Determine the number of U.S. congressional bills with a direct connection to cancer.
Strategy 2	Determine baseline levels of knowledge and legislative support for the Montana CCC Plan and public health infrastructure by adding CCC related questions to the American Cancer Society Legislative Survey in 2006.
Strategy 3	Develop state and federal political support for the Montana CCC Plan and the public health infrastructure needed for its implementation.
Strategy 4	Establish a legislative work group for the Montana Cancer Control Coalition (MTCCC) in 2005. Link cancer-related legislation to the Montana CCC Plan.
Strategy 5	Educate and update state and federal legislators on the Montana CCC Plan and progress toward implementation and outcomes: <ul style="list-style-type: none"> • Generate an annual progress report. • Provide progress reports to legislative leadership and committees working on health-related issues. • Provide state, tribal, and federal legislators with MTCCC position papers on key issues.
Strategy 6	Involve state, tribal, and federal legislators in implementing the Montana CCC Plan.
Strategy 7	Build a base of advocacy for the Montana CCC Plan and affiliated stakeholder groups. Identify policies that can support the plan.
Strategy 8	Educate cancer survivors and their loved ones on the importance of being involved in the political process in a variety of ways, including voting, serving on committees and taskforces, serving as lawmakers, lobbying, and educating.
Strategy 9	Develop guidelines for MTCCC members to use when working with legislators and decision makers. Communicate priority legislative issues to stakeholders and healthcare providers with position papers.



Advocacy Websites

- www.acscan.org
- www.canceradvocacynow.org
- www.plwc.org
- www.cancercare.org
- www.cancersurvivaltoolbox.org/
- www.cdc.gov/cancer/survivorship
- www.cansearch.org/policy

AMERICAN CANCER SOCIETY

Call toll free:
1-800-ACS-2345
(1-800-227-2345)

Objective I.2: *Increase public support for Montana's CCC Plan.*

Baseline: There is limited awareness of the CCC Plan, as reflected by the fact that there were no news items mentioning the Montana Comprehensive Cancer Control Plan in 2004

Outcomes: Beginning in 2005, public interest in, and awareness of, the Montana CCC Plan and the issues surrounding cancer will increase annually

Data sources: Results of media coverage tracking; annual number of hits on the Cancer Control webpage; number attending periodic Montana Cancer Control conferences

Strategy 1	Track coverage of Comprehensive Cancer Control Plan activities in the media, hits on the webpage, and attendance at Montana Cancer Control conferences.
Strategy 2	Refer to the CCC Plan when implementing each strategy and tactic.
Strategy 3	Develop and execute a communication plan for the implementation process that includes press releases, the webpage, presentations, and other materials.
Strategy 4	Hold statewide public forums during fall 2005 to introduce the draft CCC Plan.
Strategy 5	Sponsor periodic Cancer Control conferences; use as venues to promote the Montana CCC Plan.
Strategy 6	Distribute an annual progress report.
Strategy 7	Engage the media: <ul style="list-style-type: none">• Develop relationships with Montana's media outlets.• Provide the plan to the media.• Periodically provide the media with updates.• Provide media with story ideas on the face of cancer.
Strategy 8	Provide multiple opportunities for the public to participate in the implementation process.

Montana has
the 31st
highest overall
cancer
incidence rate
and
the 33rd highest
overall mortality
rate among
the 50 states
and the District
of Columbia.

Survivors face numerous issues throughout their diagnoses and treatments, and for the remaining years of their lives. Many of these issues could be addressed through coordinated public health initiatives. — *A National Action Plan for Cancer Survivorship: Advancing Public Health Strategies*

Objective I.3: *Build the capacity needed in the Department of Public Health and Human Services (DPHHS) staff and Montana Cancer Control Coalition infrastructures to execute the CCC Plan.*

Baseline: Existing communication systems and staffing time dedicated to implementing the Montana CCC Plan

Outcomes: By 2007, fill the positions (private and public) necessary to execute the CCC Plan; implement the plan within the established timelines; establish a functioning listserv; ensure that all legislators and key decision makers know of the CCC Plan as they move into the 2007 and 2009 legislative sessions

Data sources: DPHHS and stakeholder reports; legislative poll

Strategy 1	<p>Develop the internal and external communication structures to carry out the implementation process and build the relationships needed to foster an environment conducive to change.</p> <ul style="list-style-type: none"> • Develop communication systems within DPHHS, the Chronic Disease Department, the steering committee, and other key stakeholders. • Develop an external communication system to educate and involve medical associations, medical service providers, private sectors, state administration, state legislature, congressional delegates, survivors, tribal governments, media, other chronic disease groups, and local communities. • Create a listserv for stakeholders to communicate with one another.
Strategy 2	Develop and/or revisit a clear understanding of stakeholder roles and responsibilities within the context of implementation.
Strategy 3	<p>Develop a plan to expand public health infrastructure and the infrastructure to support the Montana Cancer Control Coalition.</p> <ul style="list-style-type: none"> • Assess existing infrastructure; identify and resolve gaps. • Identify and provide the training and technical assistance necessary to execute the CCC Plan. • Clearly define a timeline for implementation activities with checkpoints and accountability.

Objective I.4: *Secure the resources needed to execute the CCC Plan.*

Baseline: The Centers for Disease Control and Prevention (CDC) implementation grant

Outcomes: By 2007, raise the in-kind and cash resources needed to execute the prioritized strategies of the CCC Plan

Data sources: Montana CCC program financial reports; periodic stakeholder reports to be established

Strategy 1	Establish an expertise workgroup to work with public, private, and nonprofit stakeholders to identify existing in-kind and cash resources that can be utilized for implementation; periodically poll stakeholders about the resources used for plan implementation.
Strategy 2	Assess existing infrastructure for resource needs.
Strategy 3	Develop and execute a resource acquisition plan that includes making requests to private and nonprofit stakeholders and identifying the funding roles of local, state, and federal governments.

“Never doubt that a small group of thoughtful committed citizens can change the world. Indeed, it’s the only thing that ever has.” — Margaret Mead



Lois Fitzpatrick is an academic librarian and a ten-year survivor of breast cancer. She was the one who found her cancer – she spotted a dimple in the mirror, checked, and found a lump. Within two days, she'd gotten in to see her doctor. He didn't waste any time, either. She found herself at a surgeon's office almost immediately. Because she is a librarian, she'd already done a lot of research. While she was in the operating room for a surgical biopsy, she heard the doctors say something about a frozen section and she knew it was cancer. Lois had the biopsy on Monday; on Thursday she had a lumpectomy. The cancer was Stage One, and hadn't spread to the lymph nodes.

Lois had just turned 43 and had two young daughters at home. She was terrified that she wouldn't see her daughters finish growing up. She got several opinions on next steps, and thoroughly researched them. Ultimately she decided to fight back aggressively, with everything she could. Lois chose to undergo chemotherapy, radiation, and hormone therapy.

"I wanted to beat the life out of the cancer, so I went through the whole series. I would do it again. In retrospect, I made all the right decisions. First I advocated for myself by doing my research. I decided I had to be a 100 percent full participant. I wanted to be very clear that this was not going to be something done to me. This was going to be something I was doing for myself."

The ten years of survivorship have been busy ones. Lois talks with many women who have breast cancer, and she's worked with the American Cancer Society, Susan B. Komen, and has become certified as a breast self-exam instructor. When she's working with women, she encourages them to ask the hard questions. Lois believes that information is power, and she's working hard to empower other women.

"I try to help others. I lobby to get bills through. I get the word out. I want to be a voice for those women who can't speak for themselves. That's why I lobby; why I testify. We've got to keep finding new and better ways to beat this thing." — Lois Fitzpatrick

Suggestions for effective communication with a healthcare team:

- Become a partner and actively participate in the cancer care plan.
- Develop and expect an attitude of respect and cooperation.
- Provide accurate information about family history.
- Keep a list of questions for doctors or other team members.
- Take notes when having important conversations with doctors.
- Ask for explanations of anything you don't understand.
- Inform team members of concerns.
- Have reasonable expectations about the time team members can spend.
- Let team members know the patient's care preferences.
- Develop positive relationships with team members.
- Expect confidentiality.
- Recognize and accept that communication and other problems will occur.
- Address confusion, frustrations, or disagreements directly.

— Adapted from American Cancer Society *Understanding the Healthcare System*

Advocacy: What You Can Do

- **Get involved** with the Montana Cancer Control Coalition and comprehensive cancer control activities in your community. Complete and mail the member information form included in this document, page 65.
- **Talk to your lawmakers** about cancer issues — early and often.
- **Support funding** for Montana Comprehensive Cancer Control Plan implementation projects.
- **Attend** an annual Montana cancer control conference.
- **Remain informed** on cancer control issues.